

PARENT INFORMATION for Inconclusive Initial Newborn Screening Test for Cystic Fibrosis (CF)



When your baby was born a small sample of blood was taken from your baby's heel to test for certain conditions. These conditions usually can not be found simply by looking at your baby, so that is why the blood test is so important.

The results of your baby's screening test were "**inconclusive**" for a disorder called Cystic Fibrosis (SIS-tic FY-bro-sis). It is important to remember this is only a screening test.

? What does an "inconclusive" screen mean?

A small percent of all babies screened will be identified as "inconclusive" on the screening test and most of these are later found to not have the disorder. A new specimen needs to be collected from your baby and tested to help diagnose or to rule out this disorder. The Nebraska Newborn Screening Program recommends this be done at about 2 weeks of age. Keep in mind that the new test could show that your baby doesn't have cystic fibrosis.

👉 What is the next step?

Be sure to follow your baby's doctor's instructions for getting a new specimen for further testing.

? What exactly is Cystic Fibrosis (CF)?

It is an inherited genetic disorder. A person inherits the disease from their parents. CF affects about 30,000 Americans and is not contagious. Children who have cystic fibrosis are born with the disorder, but often do not show

visible signs of disease for weeks, months or even years. CF affects each person differently.

CF causes the body to produce an abnormally thick, sticky mucus that can clog the lungs, pancreas and other organs. This can lead to lung and digestive problems, which are treatable. A baby with CF will need regular medical care and a good diet.

With early diagnosis and treatment, children with CF may have improved growth and development, fewer hospitalizations and regular monitoring may prevent or reduce lung infections.



What can I do to prevent these effects?

The most important thing you can do is to be sure that your baby goes in for a new specimen to be collected and tested.

You may have already done this, but now is also a good time to be sure your baby is covered by your health insurance provider.

This could be a false alarm, but if it turns out your baby has cystic fibrosis new research and treatment has greatly improved the quality and length of life for those affected. As a result, children with CF should not be limited in their future goals and plans.

Repeat Dried Blood Spot Filter Paper Test

Collect at: _____
(place)

Date: _____

For more information talk with your baby's doctor or you can contact the Nebraska Newborn Screening Program at (402) 471-6558. Also you may want to visit the Cystic Fibrosis Foundation's web site at www.cff.org.